Making Visible the Invisible: Using Photovoice to Understand Living with Brain Injury

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Abstract. Rehabilitation professionals have advocated for gaining an insider or participant perspective on living with disability, including brain injury, and facilitators and barriers to rehabilitation (Prigatano, 2000). Involving people with a disability in research about their lived experience may increase the relevancy of research to real-life situations (Rich et al, 2000) and provide an opportunity for those with a chronic condition to play a participant-expert role in the research process (Booth & Booth, 2003; Bruyere, 1993; Balcazar et al, 1998). Action research in the tradition of Kurt Lewin involves integrating science and practice in a dynamic group setting and emphasizes the combining of science and social practice (Adelman, 1993). For this study, carried out from September-November 2006, members of the ‘Amazing’ Brain Injury Survivor Support Group in Framingham, MA participated in a 10-week photovoice project (Wang, 1998), supported by BIA-MA and SHIP. The participating survivors, having received their injuries between three and 31 years prior to the start of the project, six are traumatic brain injury survivors, one had a malignant brain tumor, and another had a non-malignant brain tumor with co-occurring stroke.

Study Design. This was a participatory action research study using photovoice, a type of action research in which people represent their lives, points of view, and experiences using photographs and narratives (Adelman, 1998). Action research in the tradition of Kurt Lewin involves integrating science and social practice in a dynamic group setting (Adelman, 1993). The first author, a doctoral student with extensive photovoice experience, co-facilitated this project with her two co-authors: the support group founder and a group member with photovoice experience.

The photography and discussion phase lasted 10 weeks, from September to November 2006. Using disposable cameras with 27 exposures, the participants took photographs of living with brain injury from their perspective and discussed them together as a group. They wrote narratives for images that they selected for exhibit, and grouped their photographs and narratives into nine categories. They held a trial exhibit and reflected on their experience with this project. The group initiated an outreach phase in January 2007, and their efforts are ongoing.

Implications for Policy and Practice. Rehabilitation professionals have long advocated for gaining an insider or participant perspective on living with disability, including brain injury (Prigatano, 2000). Involving people with a disability in research about their lived experience may increase the relevancy of research to real-life situations (Rich et al, 2000).

References